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The Société Alzheimer Society of Ottawa-Hull *Day Away/Home Assistance Programs:*

History and Program Descriptions

Prepared for the
Ministry of Community and Social Services
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Introduction

The Day Away/Home Assistance Programs have been established as a result of the concerted effort of health and service professionals and members of the Société Alzheimer Society of Ottawa-Hull who were concerned over the lack of services available to Alzheimer's Disease individuals and their caregivers. Home and day care services were initially established on a volunteer basis and eventually funded as conjoint programs.

The Day Away program is funded by the Ministry of Community and Social Services and the Home Assistance Program is funded by the Ministry of Health. Programs share staffing and resources and are both administered by the Société Alzheimer Society of Ottawa-Hull. The programs are being evaluated as a service delivery model for Alzheimer's individuals living in the community by the Ministry of Community and Social Services.

The history of the development of these programs from volunteer services to government-funded demonstration projects has been documented. The operation of each program is described in detail and client and caregiver characteristics are presented for clients who have participated in the programs over the initial six months of program operation.

Program History

The process that led to the development of a funded, innovative program to provide a day program and home assistance to Alzheimer's Disease individuals and their caregivers is

particularly interesting. A major gap in service was recognized by a number of persons from different sources who then worked together to remedy the situation.

The Société Alzheimer Society of Ottawa-Hull (hereafter referred to as the Alzheimer Society) was started by Madeleine Honeyman in September 1980 in her home. It was incorporated in 1982 and presently is located in an office staffed by five permanent volunteers, with a membership of 450. It was to the Alzheimer Society that concerned professionals from three sources came to try to seek a solution to problems of accessing treatment services for Alzheimer's individuals.

In 1982, professionals from the Royal Ottawa Hospital approached the Alzheimer Society with their concern for Alzheimer's patients who were unable to access Chronic Home Care. Persons with Alzheimer's Disease were not recognized as having a disability requiring professional services. At that time, volunteers with the Alzheimer Society were providing counselling to their membership in their homes. It was felt that a Home Assistance program should be developed whereby two or three professionals would provide services in the home when Chronic Home Care was inaccessible. A proposal for a Home Assistance Program was submitted to the District Health Council, but was turned down at that time, and resubmitted in 1984.

In early 1983, Fran Hadley (R.N.) also approached the Alzheimer Society with her realization that Alzheimer's Disease individuals did not "fit" into day programs operated for the elderly. For a field placement for the Rehabilitation

Certificate Program at Algonquin College, she studied day centres for the elderly and noted that it was most often Alzheimer's individuals who left the programs, or "fell between the cracks." In 1983 only one day hospital and two day care programs for the elderly were available. Programs were geared toward rehabilitation and did not address the needs of Alzheimer's Disease patients. Rehabilitation is not possible for Alzheimer's individuals. They are often viewed as "uncooperative" rather than disabled in a setting that focuses on rehabilitation as opposed to habilitation. Due to their disability they need a one-to-one relationship with a familiar staff person and a safe environment, as wandering is frequently a problem.

At approximately the same time St. Patrick's Home for the Aged also approached the Alzheimer Society as they had several Alzheimer's patients who did not fit into their day program. They offered their facility for a day program for Alzheimer's individuals if the Alzheimer Society would provide staffing. Fran Hadley offered her services on a volunteer basis one day/week for one year to develop and implement a therapeutic day program for Alzheimer's individuals. She assembled other volunteer professionals and in November 1983 the Day Away program was launched.

Following a comprehensive assessment of health and personal needs and functional abilities in activities of daily living, an individualized program for each client was constructed. A full day of respite was provided for the caregiver and a socialization experience was provided for the client. In addition, family members were provided

with techniques to be used in the home, based on program workers' experiences with the client during the program.

Volunteer professionals included R.N.'s, psychologists, and a social worker technician. The Ottawa General Hospital Psychogeriatric Clinic offered their occupational therapist, who had a background in epidemiology, on a consultative basis one-half day per week. Personal time donated by many of these staff members amounted to much more than one day per week. Client assessments, charting and general management of the program had to be completed. In addition, the program was constantly being revised based on feedback from client, caregivers and volunteer workers. At the start of the program the client to volunteer ratio was 1:1, however, as clients became more familiar and comfortable with the program, two clients were assigned to a volunteer worker.

It was expected that the program would serve four clients who were in the early stages of the disease on a one day per week basis. However, it was not long before eight to ten clients were attending the program with an equal number on a waiting list. These clients tended to be in the later stages of the disease. Families of Alzheimer's Disease clients frequently do not seek help until a crisis in the family occurs at which point the client is often in the later stages of the disease.

An evaluation of this pilot project was conducted in which clients in the program were compared with those who were unable to attend either because the program was full and so they were placed on a waiting list, or because of

lack of transportation or refusal to come. Treatment and control groups were assessed at initial contact with the program and were retested six months later on screening tools measuring dysfunction in behaviour, including the Rapid Disability Rating Scale and the Functional Dementia Scale. While both groups deteriorated, the control group appeared to have a greater level of deterioration than the treatment group. The treatment group maintained perceptual and social skills better than the comparison group.

In the spring of 1984, Hadley and Honeyman submitted a proposal for funding of the Day Away program to the District Health Council. Both the Home Assistance proposal (which had been resubmitted) and the Day Away proposal were approved for funding. It was decided to combine the two programs in terms of staff and resources as the programs were interrelated. The Ministry of Health agreed to fund the Home Assistance Program and the Ministry of Community and Social Services agreed to fund the Day Away Program, as the responsibility for day care falls under its mandate. The Day Away Program was funded as of November 15, 1984 and the Home Assistance Program received funding March 1, 1985.

Physical Site, Staffing and Administration

A. Physical Site

The program is housed at the Elisabeth Bruyère Health Centre. Extensive renovations were required to create a home environment for the Day Away program and office space for both programs.

A large room was divided into kitchen, dining, and living room areas, and decorated to create a homey atmosphere. A bathroom easily seen and accessible was installed on-site and a cloak room to remove outer clothing was included. Care was taken to reduce unnecessary sensory stimulation. Walls, ceilings, and doors were sound insulated, walls were papered with vinyl wallcovering and a non-patterned floor was installed to reduce perceptual distortion. The room can be divided into two areas with an acoustic sound proof door divider. It is important that walkways and furniture lay-out be straightforward and the environment uncluttered. Locks were placed high on doors leading to corridors as a safety feature to prevent wandering. A one-way mirror was installed for visiting professionals. Staff or volunteers not directly involved in the day program are discouraged from entering the program area during program hours. Staff now wish that more space had been allotted to the kitchen area as clients enjoy meal preparation activities and are relaxed and informal in their interaction in the kitchen area.

B. Staffing

Staff and resources for the two programs were combined as they are very much interrelated in objectives, activities and client group served. Although each program has staff who work exclusively with one program, the program director, occupational therapist, family support co-ordinator and social worker are shared.

There are a total of 5.7 full-time equivalent staff;

2.4 full-time equivalents in the Home Assistance Program and 3.3 full-time equivalents in the Day Away Program. The programs are staffed as follows:

Table 1

Professional Staffing of the Day Away/Home Assistance Programs

Type of Staff	Full-time Part-time	% H.A.	% Day Away
Program director (R.N.)	F.T.E.	36	64
Assistant program director	F.T.E.		100
Family support co-ordinator	F.T.E.	40	60
Social Worker	F.T.E.	40	60
Occupational Therapist	.7	30	70
R.N.A.	.5	100	
Recreologist	.5	100	

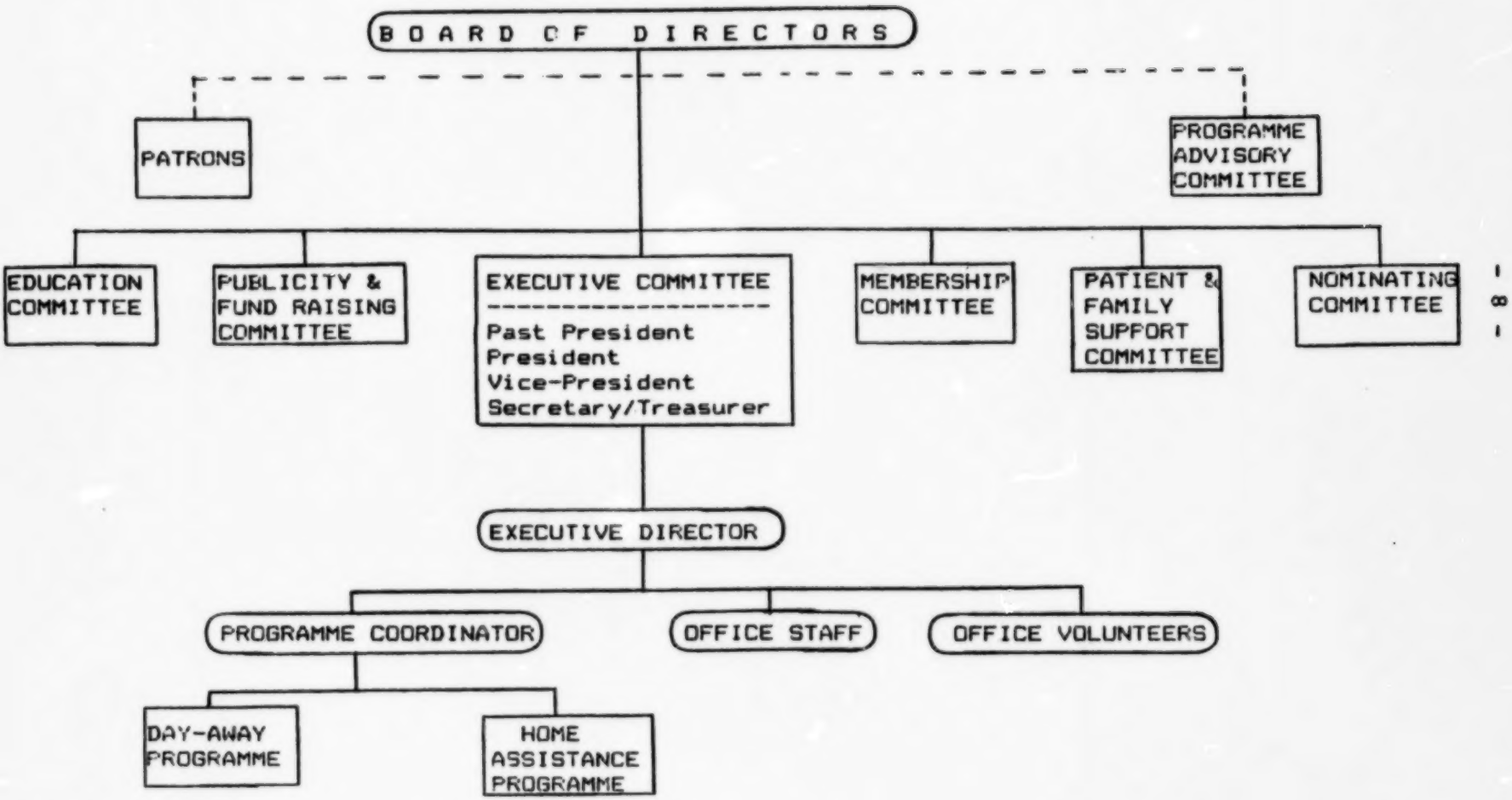
These programs have been staffed by a highly-trained multi-disciplinary team of professionals who are working to develop a unique model of service for a client group whose particular neeeds have not been met in the past. Job descriptions appear as Appendix A.

C. Administration

The programs are administered by the Société Alzheimer Society of Ottawa-Hull. Figure 1 shows the organizational chart of the Society. The Day Away/Home Assistance Programs are managed by a program director. She is responsible

Figure 1 SOCIETE ALZHEIMER SOCIETY OF OTTAWA-HULL 6 July 85

ORGANIZATION CHART



for planning, organizing, directing, staffing and evaluating the programs. Currently, she reports on a weekly basis to the Executive Director of the Alzheimer Society. The Executive Committee is responsible for program decisions relating to the budget, staffing, and personnel policy which are presented to the Board for approval. The Board of Directors has the ultimate responsibility and accountability for the Day Away and Home Assistance Programs. The Board also contributes to and ratifies program policy and is responsible for fiscal management. A Program Advisory Committee is to be established consisting of representatives from the District Health Council, Council on Aging and from geograpnical locations around the Ottawa-Hull area. The Program Advisory Committee will advise the program of needs in the community.

The administration by a volunteer agency of conjoint community-based programs for Alzheimer's Disease individuals funded from two provincial government ministries has required major time commitments from the president, vice-president and treasurer. The Alzheimer Society will continue to administer and supervise the programs until they become free-standing, established programs.

In terms of funding, the Ministry of Community and Social Services has provided $142,000 for operating costs of the Day Away Program and the Ministry of Health has provided $3,400 capital allowance and $64,500 for operating costs of the Home Assistance Program to the end of fiscal year 1985-86. The Ministry of Community and Social Services is also funding an evaluation of the programs to be completed by the end of 1985. The Alzheimer Society contributed $19,000

for capital costs including renovations and is committed to any shortfalls on operating expenses, e.g., OHIP payments for three staff members and any additional monies required for transportation of clients not met by government funding. Kiwanis contributed $2,000 for furniture. Clients attending the Day Away program are charged a $10.00 per day user fee to cover consumable program items (e.g., food, transportation).

This program has been time-consuming and complicated to administer given the necessity of responding to two Ministries, including the preparation of separate financial statements and program statistics.

Program Description

A. Client Referral

Clients are referred to the program from many sources as listed below:

Table 2 Referral Sources of Clients

1. Placement Coordination Service
2. Alzheimer Society
3. Family Physician
4. Day Hospitals
5. Day Care Facilities
6. Psychological Assessment Unit
7. Geriatric Assessment Unit
8. Family
9. Friends
10. Self
11. Chronic Home Care
12. Alzheimer and Memory Disorder Clinic
13. Regional Special Services

Referrals received from a source other than Placement Coordination Service are directed to the Placement Co-ordination Service. Involvement with Placement Coordination Service is initiated to prevent duplication of services, to identify the most appropriate facility for the client, to put clients on record for future placement and to make families aware of placement facilities, e.g., nursing homes, boarding homes, day care centres.

Placement Coordination Service sends a letter to the client's physician requesting a neurological assessment if none has been done. The Alzheimer and Memory Disorder Clinic (Ottawa General Hospital) is most often used. The referred individual must have a diagnosis of Alzheimer's Disease confirmed by a neurologist and/or a geriatrician and be living in the community to be eligible for admission into the program. Persons with Alzheimer's Disease living in institutions will not be accepted. A general form is mailed to the family and a functional form is sent to the public health nurse for completion as needed.

B. Home Assessment

During this process, a home visit is made. A professional staff member is assigned to visit referred clients to determine their suitability for the program with the exception of the Assistant Program Director who spends all of her time on-site with the Day Away Program. A number of criteria are used to assign staff members to new cases, including language spoken, demonstrated need for a particular type of professional or type of program, and current distribution of clients among staff. Each staff member is responsible for processing his/

her own caseload and will access other staff members for their expertise as required.

Clients are assessed for their suitability to the Program in their home, as it is a familiar non-threatening environment. The home assessment may entail two or three visits depending on how comfortable the client is with the staff member. The first visit focuses on developing a rapport and trust with the client and caregiver. The second and occasional third visits involve the administration of the Protocol and the Hierarchic Dementia Scale. The Protocol collects general information, medical histories of client and caregiver, problems identified by the caregiver, and past social, occupational and family history. A functional evaluation in terms of Activities of Daily Living and home-making skills is also completed. The Protocol is completed with the caregiver. The Hierarchic Dementia Scale includes measurements of cognitive, language, perceptual, motor and functional abilities and is completed with the client. The Hierarchic Dementia Scale provides information which is used to devise an individualized program for the client. If necessary, two staff members attend the home visit to administer the Protocol and Hierarchic Dementia Scale. While one staff member administers the Hierarchic Dementia Scale with the client, the other staff member completes the Protocol with the caregiver who may not wish to discuss problems with the client present.

The Family Burden Index provides a measure of level of stress the caregiver is experiencing. This form is frequently left with the caregiver to complete and return at a later date. Areas of stress identified by the Family Burden Index may be addressed by the appropriate staff member

(occupational therapist, social worker, nurse, family support person) or referrals made to appropriate community agencies.

Upon completion of the assessment, a summary report is written by the case manager which includes the Protocol, Hierarchic Dementia Scale and Family Burden Index and recommendations for admission to either program. Assessment instruments are located in Appendix B. Monday mornings are reserved for completing assessments.

In general, clients who have a need for social interaction, and clients whose caregivers need respite are referred to Day Away. The Home Assistance Program meets the needs of clients who are resistant to leaving the home, clients in frail physical health and those who have transportation problems.

C. The Day Away Program

Based on the results of the neurological assessment and the home assessment components, a team conference is held to discuss the suitability of the Program for the client. The reasons for admission are identified. During the first six weeks of admission to the Program, assessment of functional and social abilities continues. At the end of this period a second team conference is held to determine whether the client should remain in the program. Clients are formally admitted at this time. An individual management program is developed for the client based on assessment results and observations from team members over the six week period. Specific problem areas are identified and addressed in an individual client and family care plan.

Three groups of eight clients each attend the program one day per week, Tuesday, Wednesday or Thursday from 9:00 a.m. to 4:00 p.m. The client to staff ratio is 4:1. One of these day groups is French-speaking and two are English-speaking. The creation of a French-speaking group has improved the functional level of French-speaking clients who were previously mixed with English-speaking clients.

A half day Monday morning program (9:00 a.m. to 1:30 p.m.) is provided for an intake group of six clients who will eventually enter one of the full day programs. Fridays are reserved for staff education, charting and program development.

A small number of Day Away spaces are used for "interim" clients, i.e., those clients who require institutional placement and are currently on a waiting list. These clients may not receive comprehensive assessment and program planning. However, a plan is developed and included on a discharge summary to the receiving facility. The emphasis in these cases is on providing support to families during the transition to institutional care.

There is a mixed level of dementia in each of the day programs. This has been found to be beneficial to both clients and staff. Clients assist one another and, as some clients are able to function independently in many areas, more staff time can be directed to those requiring more care.

The objectives of the Day Away program are:

1. To delay the institutionalization of the client with Alzheimer's Disease, while maintaining the optimum quality of life.

2. To reduce the burden to the caregiver of caring for the client with Alzheimer's Disease.

3. To maintain for as long as possible the functional level of behaviour in the client with Alzheimer's Disease.

4. To develop a standardized approach to the care of the client with Alzheimer's Disease.

5. To increase the awareness of the community and the knowledge of professionals regarding the effective management of the client with Alzheimer's Disease.

Daily Program

A daily program schedule is followed to maintain consistency and create a familiar routine. An outline of program activities is presented below:

- Arrival

  Clients arrive at 9:00 a.m. Seventeen of the clients are provided transportation from their home to the program by a hired limousine service at a cost to the program of $40 per day. Staff assist in providing a relaxed entry, care of personal items and distribution of name tags.

- Orientation period

A board constructed by program clients is used to affirm the place, date and weather. A theme is chosen for discussion, in most cases revolving around the day's activities.

- Activity period

Activities may include crafts, woodworking, or activities of daily living. Activities chosen have an end purpose, are adult oriented and designed to tap residual skills and provide a sense of achievement. Opportunities are provided for the client to produce a finished product to give someone.

- "Coffee break"

This is primarily a time for socialization when ideas and past and present experiences are shared.

- Exercise period

The objectives of the exercise program are to provide mobility, strength, body awareness, interaction and a sense of well being. The exercises are simple and repetitive which allows the client to complete the program with minimal assistance.

- Individual programs

If time permits, individual programs are started. This gives the client an opportunity to express opinions, maintain individual skills and socialize on a one-to-one basis.

- Meal preparation, lunch

  Clients prepare the soup and dessert. They set and clear the table and wash and dry the dishes. During this time nutrition is discussed in a conversational way. A hot meal is provided through the Elisabeth Bruyère Health Centre kitchen. This relieves the caregiver of having to prepare a large evening meal.

- Activities of daily living

  Many Alzheimer's Disease clients require specific step-by-step instructions within the context of the situation and ongoing supervision to guide them through the sequences of a task. In many activities of daily living (e.g., meal preparation, eating, dressing/undressing), staff provide specific motor planning for clients having difficulty completing a task. A regular toileting schedule is essential in the program for those clients who have difficulty sequencing steps required to go to the washroom, or expressing the need to use the toilet.

- Gross motor activities

  These may include a walk, shuffleboard, bowling or a bean bag toss. These activities provide the client with fresh air, an outlet for energy through physical activity, and a chance to explore the environment.

- Relaxation and socialization period

  This is a time to wind down with a sing-along or listening to music. Clients may enjoy a cup of tea or coffee, or a sherry.

This basic outline of daily activities is flexible and interchangeable. When the weather is fine, outings are arranged by the recreologist and may include strawberry picking, cruising on the Ottawa river, picnics and barbecues.

Although much of the program is social in nature, there are many therapeutic components. Clients all have individual programs designed to meet their individual needs. Program activities are broken down into many steps, ensuring that each person is able to participate in the activity in some way and therefore contribute to group cohesiveness. Within a group setting, individual programs are carried out for each client by carefully planning program activities and social interactions which take into account the capabilities of each group member.

Clients enrolled in the Day Away Program also receive Home Assistance. It is important that the individual program established during the client's day away be reinforced at home by the caregiver. Home Assistance to Day Away clients is typically limited to one or two visits initially and then as requested by the caregiver. Most caregivers participate in maintaining a journal which records experiences with the client over the week. In turn, staff record in the journal the day the client attends the program. The journal allows for close contact between staff and caregivers, identification of potential problems before a crisis evolves and feedback on management techniques for identified problems.

All Day Away clients are re-evaluated at six month intervals, including the readministration of the Hierarchic Dementia Scale and the Family Burden Index and revision of

the plan of action if required.

D. The Home Assistance Program

The Home Assistance Program provides one visit per week for an average of four weeks. The first two visits focus on collecting assessment information. An interdisciplinary team conference is then held, including program staff and when required other professionals, to develop a plan of action which is reviewed with the caregiver. Typically a plan of action would include the development of a program of management techniques for the home (e.g., toileting, bathing, dressing) and accessing of existing community-based services, most commonly Chronic Home Care. At the final home visit, the staff member may visit the home with the staff member of the referred agency in order to review the plan of action, ensure management techniques are clearly understood and that case management can be carried on by the referred agency and/or the caregiver.

The Home Assistance Program attempts, where possible, to transfer case management to the appropriate community-based agency in order to avoid duplication of service. They provide their expertise in assessment and teach appropriate management techniques to caregivers and other agency staff who may care for the client. In conjunction with the caregiver, the Home Assistance case manager determines what resources are required to maintain the client at home and reduce the stress on the family, or, where necessary, assists in procuring facility care and provides counselling to the family during this process.

As soon as other staff or volunteers are in place, Home Assistance is discontinued. Home Assistance is maintained only in cases in which required services cannot be accessed from other existing agencies.

The provision of counselling and education to the caregiver is an important component of the Home Assistance Program. Education and counselling are often required in preparing the caregiver for the client's care in the future. Information on the disease process prepares the family for what to expect as the client enters each stage of the disease. As most clients will eventually require institutionalization, families must be prepared for this step. An emergency checklist may be prepared with the caregiver, e.g., procedures to follow should an emergency occur involving either the caregiver or the client. Caregivers are assisted in seeking and qualifying for other services. Information is provided on legal aspects concerning the recent Public Trustee Act amendment which enables the caregiver to retain power of attorney upon declaration of incompetency of the Alzheimer's Disease client.

Many clients and caregivers also require counselling over the course of the disease. Counselling is provided to both clients and caregivers on their feelings of loss, anger or frustration. Counselling may also centre around problems in relinquishing care of the client to a professional who enters the home to provide care and respite.

Under the auspices of the Home Assistance program are the Family Support groups. To assess interest in the formation of family support groups, a telephone survey was conducted with 204 Alzheimer Society members. Sixty-seven

persons (33%) indicated interest in attending a support group and, as a result, two Family Support groups were established.

Groups are advertised to the Alzheimer Society membership and the general public. They are not limited to families enrolled in the Home Assistance program. A range of 12 to 31 persons attend each meeting. Meetings are held every two weeks for seven sessions beginning with an information session to determine the interests of the group. Following the seven sessions, the Family Support Worker acting as group leader will assist in the transition to a self-help group, if desired, but will not participate within the group on a long-term basis. One French-speaking group in Ottawa group is being considered while three English-speaking groups are currently operating.

The objectives of the Family Support groups are:

(a) to provide an opportunity for the caregivers to discuss their problems and share their successes and failures in a supportive atmosphere

(b) to provide information on community resources available.

(c) to provide information on drug interactions, autopsies, diagnostic procedures, disease process and management techniques

(d) to provide opportunities to listen to guest speakers (e.g., neuropsychologist, occupational therapist, a person with Alzheimer's Disease)

At the end of the sessions, phone numbers are exchanged and evaluation sheets are completed to help with future planning. Three information binders have been compiled by the Family Support Co-ordinator for self-help groups. One binder provides information on how to set up and run family support groups, one provides an inventory of available resources in Ottawa and the third consists of updated literature on family support groups. Included in these information binders are two booklets: Coping and Helping with Alzheimer's Disease, National Advisory Council on Aging, January 1984 and Alzheimer's Disease A Family Information Handbook, Health and Welfare, Canada. These information binders will be provided to groups who continue without the participation of the Family Support Worker as group leader from this program and to new groups established and run by individuals in outlying areas.

Individual and group counselling sessions were provided until recently for family members of the Day Away/Home Assistance programs; however, the Alzheimer Society Board of Directors advised cancellation of this service as it was felt the Family Support groups filled this need.

E. Referral Agencies

Both the Day Away and Home Assistance programs refer to a variety of agencies for assessment and treatment services. The services most frequently utilized are described here.

(a) Assessment Services

1. Alzheimer and Memory Disorder Clinic, Ottawa General Hospital

   - A comprehensive assessment battery for

Alzheimer's Disease has been developed by a neuropsychologist and a neurologist at the Alzheimer and Memory Disorder Clinic. Clients who have not had a recent neurological assessment are referred through their physician to the Clinic and assessment results are provided to the program. The Clinic, in turn, refers diagnosed Alzheimer's Disease individuals to the Day Away/Home Assistance program.

2. Geriatric Assessment Unit, Ottawa Civic Hospital

   - Clients may also be referred by their physician to the Geriatric Assessment Unit for assessment by a geriatrician who provides assessment results to the program.

3. Neuropsychologist Consultant, Dept. of Psychology, Elisabeth Bruyère Health Centre

   - A neuropsychologist attends case conferences and has been teaching staff to interpret assessment results. To date, his services have been offered free of charge. Funds have been requested to provide payment on a fee-for-service basis.

4. Elisabeth Bruyère Day Program

   - Clients are referred to this program for assessment review if another cause of dementia

is suspected, and if the client is unable to access other assessment facilities for a neuropsychological work-up.

5. Ottawa General Hospital Psychogeriatric Clinic

- Referrals are exchanged with this community-based psychogeriatric clinic.

(b) Treatment Services

1. Chronic Home Care

- The Program Co-ordinator initiated contact with Chronic Home Care as, when the Day Away program began, clients attending a day program did not qualify for Home Care. This policy was altered last year and currently all clients attending geriatric day care are eligible for Home Care. Clients who attend geriatric day care are provided with Home Care for a three month trial period at which time their needs are re-evaluated. This is done to prevent duplication of service. A plan for linking the two services is presently in proposal format.

2. Regional Special Services,
Ottawa-Carleton Social Services Dept.

- Nursing, homemaking and home support services are requested for Home Assistance clients

not eligible for Chronic Home Care. These services are provided primarily for clients at high risk, (e.g., those living alone who do not qualify for Chronic Home Care), on an interim basis until facility care can be arranged.

3. Ottawa General Hospital Psychogeriatric Clinic

   - Clients are referred to this community-based clinic for psychiatric problems such as depression or fear of leaving the home.

4. Respite Bed Care

   - Although the program attempts to locate substitute caregivers to come into the home to relieve caregivers, this is sometimes not possible. Respite bed care is sought wherever a bed can be found, e.g., Elisabeth Bruyère Health Centre, St. Vincent Hospital, Island Lodge (Home for the Aged).

5. "You and Your Aged Parent Program", sponsored by the Centre de Jour Ainës Francophone, at Elisabeth Bruyère Health Centre

   - French-speaking family members are referred to the above program.

6. Pharmacy, Elisabeth Bruyère Health Centre

   - This community-based information service is used to sort out problems with medications

including multiple drug use and their contra-indications. Medications are reviewed and a case conference may be held or a referral made to the family physician.

Program-related Activities

1. Education of the Community regarding Alzheimer's Disease and Its Management

In-service training sessions have been provided by Home Assistance program staff to a variety of community and institution-based professionals. A training session may include information on the disease process, particular needs of and ways of interacting with the Alzheimer's Disease patient, and management techniques for individual behaviour problems. Assistance is also given to some facilities in assessment of Alzheimer's Disease patient needs and interpretation of assessment results. As requests are so numerous for in-service training workshops, the program co-ordinator feels an audio-visual training package would be a valuable program and community asset.

Program staff provides assessment and management plans to institutions for Day Away and Home Assistance clients being placed. This is intended to facilitate the admission of the client to institutional care

2. Use of Volunteers

Volunteers are essential to the staffing of the Day Away program, given the 4:1 client to staff ratio. On

average, three volunteers per day assist with program operation. Currently, students are used as part of training programs they are attending. Gerontology and second year social work students from Algonquin College receive experience in the Day Away program during the school year. During the summer, high school students from the Red Cross Summer Student Program assist in the program for two-week intervals. The summer students worked out very well despite their short placements.

An unpaid Volunteer Co-ordinator manages the volunteer program. It is hoped that this will be a paid position in the near future as it is essential to the program's operation.

3. Manual

Doing Things:
A Guide to Programming
for Clients with Alzheimer's Disease and Related Disorders

A manual directed to professionals and others involved in activity programming for the client with Alzheimer's Disease is being written by the occupational therapist in the program.

The manual is based on the premise that activity is important in meeting basic human psychosocial needs. The disease process is described in terms of its effect on an individual's ability to remain active (e.g., perceptual-motor deficits). The manual outlines how to program activities that focus on the client's assets

and residual skills to optimize competency and increase self-esteem. Activity analysis and activity grading are included to aid in activity programming that optimizes the client's chances of successfully completing the task. Activities that are most appropriate and those that have been found to be most useful in these programs are outlined. Methods of introducing and guiding clients through management techniques, including basic activities of daily living such as toileting, dressing, and grooming are included.

The manual is based on careful observation and recording of activities and techniques that were developed with the Alzheimer's Disease clients in these programs.

4. Program Evaluation

An extensive evaluation of these conjoint programs is being conducted by external evaluators through the Ministry of Community and Social Services. The major issue of this evaluation is whether a model of service can be developed and implemented which provides both appropriate and sufficient support services to Alzheimer's individuals and their caregivers. The feasibility of replicating these programs in other localities is being examined.

Program monitoring and staff activity analysis are are being conducted to examine operational outcome. Caregivers of clients participating in the programs are being interviewed to determine their perception of the usefulness of program components and suggestions for program improvement.

The major outcome variable is change in family burden as measured by the Family Burden Index developed by Zarit and Zarit in 1982. The caregiver's Family Burden Index scores at intake will be compared with six month follow-up scores. Program factors which contributed to perceived reduction in burden will be identified. In addition, intake scores on the Hierarchic Dementia Scale will be compared with six month follow-up scores to provide a measure of change in dementia.

Client and Caregiver Characteristics

Since the inception of the Day Away Program in January, 1985 and the Home Assistance Program in March, 1985, a total of 86 clients have been referred as of July, 1985 (see Table 3). Over this six-month period, a mean of 14 clients per month have been assessed for program suitability. The program co-ordinator projects 15 new cases per month can be processed, with each case receiving four home visits.

Fifty-two clients have been accepted into one or both programs, five clients were discharged prior to program involvement and 29 cases are being processed. Of the 52 clients participating in the program, 9 have been discharged. Five of those discharged were placed in institutional care and four of those discharged continue to live in the community.

The client and caregiver characteristics presented here were drawn from case record review of the 52 clients who have been accepted into the programs.

Table 3

Client Intake Over the Initial Six Months of Program Operation

Client Status	No. of Clients
Day Away and Home Assistance program participants	52
Discharged prior to program involvement	5
Case being processed	29
	86 TOTAL

$\bar{X}$ (mean) = 14 per month

Table 4
Number of Clients in Day Away/Home Assistance Program

Program Type	No. of Clients (%)
Both Day Away/Home Assistance	40 (77)
Home Assistance ONLY	12 (23)

Table 4 indicates that approximately three-quarters of clients have received both Day Away and Home Assistance. Home Assistance is provided to clients attending the day program in order to assist the caregiver in continuing with the individual program the client receives one day per week. It is important that problems with the home situation be managed as the client is at home six days per week. Approximately one-quarter of clients have received Home Assistance only. The percentage of clients receiving Home Assistance only will likely increase as the Home Assistance program has been operating for only a short time and as the day program is filled. The Day Away program currently has a waiting list of seven. Clients on the waiting list for Day Away receive Home Assistance until a day program space is available.

Case records were examined to determine time lapse between referral and "program admission". For Day Away, the date the client first attended the program was used, rather than the formal admission date six weeks later. When referral

dates were missing, date of first assessment visit was used. For clients receiving Home Assistance only, the time lapse from referral to case conference was calculated. A wide range in referral processing is apparent as some clients are admitted within a few days in cases of emergency while others are not admitted for many months. Time lapse ranged from 1 to 133 days with a median of 31 days from referral to program admission.

Table 5 presents client characteristics for clients enrolled with Day Away or Home Assistance and their caregivers. The mean age of all clients is 73 years, with a range from 52 to 84 years. Clients receiving only Home Assistance have a mean age of 77 years, while those participating in the Day Away program have a mean age of 71.5 years.

Three-quarters of caregivers are spouses of clients. Spouses have a mean age of 70 years. Twelve clients are being cared for by other relatives, with a much younger mean age of 46 years.

Almost three-quarters of clients are female, while 60% of caregivers are male. Role reversal is frequently a problem for caregivers, requiring major adjustments in personal interactions and activities.

Based on client record information, 84% of clients are in good or very good physical health. Only eight clients were listed in fair or poor health. Clients are, on the whole, physically intact with mental impairment. It is this type of client for whom it has been particularly difficult to access Home Care services or to be placed in

Table 5 Client and Caregiver Characteristics

CLIENT			CAREGIVER		
Age (n=51)	Mean	Range	Age (n=46)	Mean	Range
Day Away Home Assistance	71.5	52-82	If Spouse	70	54-83
All Clients	77	65-84	If other relation	46	30-65
	73	52-84			
Sex (n=52)	n	(%)	Sex (n=51)	n	(%)
Male	14	(27)	Male	31	(61)
Female	38	(73)	Female	20	(39)
Physical Condition (n=50)			Physical Condition (n=48)		
	n	(%)		n	(%)
Very good	4	(8)	Very good	0	
Good	38	(76)	Good	37	(77)
Fair	6	(12)	Fair	11	(23)
Poor	2	(4)	Poor	0	
Language Spoken in Home (n=50)			Relationship of Primary Caregiver to Client (n=51)		
	n			n	(%)
English	36		Husband	26	(51)
French	9		Wife	12	(24)
Both	5		Son/daughter (in-Law)	11	(22)
			Sister/brother	2	(3)

an institution. Seventy-seven per cent of caregivers are in good health.

Table 6 provides a description of the functional abilities of clients to perform activities of daily living taken from the initial interview with the caregiver. In terms of self-care, approximately one-half are able to dress, undress and groom themselves without assistance. Twenty per cent, however, are unable to bath or groom themselves even with assistance. Twenty-nine per cent either need help or are unable to manage toileting.

In terms of physical movement, most clients are able to get in and out of bed and are mobile in the home. Only three know how to use public transportation, while two-thirds cannot manage public transportation even with assistance. One-half of clients cannot use the telephone.

In terms of household tasks, with the exception of housework, the majority of clients are unable to participate in these tasks, even with assistance. Eighty-eight per cent of clients are unable to manage their financial affairs.

Many clients have difficulty expressing themselves verbally and/or have difficulty following instructions. The majority are unable to get help should an emergency arise at home. In addition one-quarter of clients are subject to wandering, requiring protective measures to be taken at home, such as locks located above where the client can easily reach.

Table 6 Functional Abilities of Clients' Activities of Daily Living

Self-care	Can Do Unassisted		Can Do With Help		Cannot Do	
	n	(%)	n	(%)	n	(%)
Bathing	19	(37)	22	(43)	10	(20)
Dressing	22	(42)	26	(50)	4	(8)
Undressing	26	(57)	17	(37)	3	(6)
Toileting	37	(71)	12	(23)	3	(6)
Grooming	27	(54)	13	(26)	10	(20)
Physical Movement						
Getting in/out of bed	39	(87)	6	(13)	0	
Mobility in house	46	(92)	4	(8)	0	
Use of transportation	3	(7)	12	(26)	31	(67)
Use of telephone	19	(40)	4	(8)	25	(52)
Household tasks						
Grocery shopping	3	(6)	10	(20)	37	(74)
Meal preparation	3	(6)	15	(29)	33	(65)
Housework	14	(28)	12	(24)	24	(48)
Laundry	8	(16)	8	(16)	33	(68)
Money management	1	(2)	5	(10)	43	(88)

Table 7 Problems Frequently Reported by Caregivers

		No. of caregivers
1.	Constant care resulting in caregiver's lack of socialization/isolation/ no personal time	13
2.	Toileting/incontinence	7
3.	Difficulty getting client out and involved in activities	7
4.	Memory/forgetfulness/attention span	6
5.	Unpredictable behaviour	4
6.	Sleeplessness/restlessness	3
7.	Resistant to instructions	3
8.	Dependent for all activities of daily living	3
9.	Wandering	2
10.	Frustration	2
11.	Depression	2

Table 7 presents the problems most frequently reported by caregivers at initial interview. The constant care required, leaving no personal time or time for socialization was by far the most common problem reported. Incontinence, difficulty in getting the client out of the home and involved in activities, and problems with memory failure were also frequently cited.

Table 7 and the data on level of client's functioning in terms of activities of daily living speak to the amount of

care required and the demands and responsibility placed on the caregiver. Those familiar with the care of Alzheimer's Disease individuals have described the care given as requiring a "36 hour day".

Other sources of support are, however, being accessed by these caregivers as shown in Table 8. Family and friends appear to be important sources of relief and many professional community services are being used to maintain the Alzheimer's Disease individual in the home, the most frequently used services being Home Care and Homemaker services.

The Family Burden Index measures the level of stress the primary caregiver is experiencing in caring for the Alzheimer's Disease client. The maximum score obtainable on the Family Burden Index is 88. The higher the score, the more stress the family member is experiencing. These caregivers scored a median of 42 out of 88, with a range of 6 to 71.

Summary

The Day Away and Home Assistance programs are both fully operational and serving the projected number of clients, i.e., 15 new clients per month. Both programs are filled to capacity. Both programs include comprehensive assessment of the client and the provision of a management plan. For Day Away clients, an individual management plan is followed during the client's day at the Program and at home by the caregiver who is taught appropriate management techniques. For Home Assistance clients, the management plan is followed through by the caregiver and other community-based agency staff to whom case management is transferred. Counselling and education of the client and

Table 8 Sources of Family Support

Non-professional Sources of Family Support

	n
Family	20
Friends	18
Volunteers	1

Professional Sources of Family Support

	n
Home Care	21
Homemaker	14
Public Health Nurse	3
Occupational Therapist	3
Other day care	2
Special transportation	2
Psychogeriatric Clinic	2
Day Hospital	1
Physiotherapist	1
Alzheimer Society	1
Regional Special Services	1
Para-med	1
CNIB	1

caregiver are essential components of both programs.

Family Support groups are operating which are open to program caregivers, Alzheimer Society membership and the general public. The program co-ordinator focused on developing a network of community resources which could be used to provide services to program clients and caregivers. Of note is the change effected in eligibility for Chronic Home Care for clients attending geriatric day care. In-service training workshops have been presented to a variety of institution and community-based professionals and a manual for professionals involved in programming is being written.

Clients serviced are in later stages of dementia than initially anticipated. Based on initial interview information, one-half are unable to dress/undress or groom themselves without assistance, 29% need assistance with toileting, the majority of clients are unable to participate in household tasks even with assistance, and 88% of clients are unable to manage their financial affairs. Clients have a mean age of 73 years. Three-quarters of caregivers are spouses, with a mean age of 70 years. Most clients are in good physical health apart from Alzheimer's Disease. The apparent good health of most Alzheimer's Disease individuals has made accessing appropriate services difficult. The most common problem reported by caregivers is the constant care required by Alzheimer's Disease family members, leaving caregivers little personal time or time for socializing.

The Day Away/Home Assistance programs are providing services to a target group for whom services had not previously been available. These programs are innovative in

that there are no standard models of service upon which to base program development. It is important that a community-based model of service be developed to meet the needs of this target group, as Alzheimer's Disease is increasing in prevalence and will present a major health problem in upcoming decades. This program fills a gap in service for those caring for Alzheimer's Disease relatives at home.